

# Men's experiences of prostate cancer care in Ireland: results from a nationwide, population-based, survey



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## Background

Patient experience of cancer care is considered an important indicator of quality-of-care. In light of service developments, we assessed the care experiences of men recently diagnosed with prostate cancer in Ireland; public and private patients were included.

## Methods

#### Sample selection

- 3,850 men diagnosed with invasive prostate cancer 5-20 months from study commencement (30/09/2012) were identified through the **National Cancer Registry**, Ireland.
- 514 were excluded during preliminary checks (e.g. deceased, treated at hospital not covered by ethical approval).

#### Screening by clinicians

- 3,336 men were eligible for 'screening' by their treating clinician, to confirm they were aware they had cancer, were still alive, and there was no other reason why it would be inappropriate to contact them (e.g. cognitive difficulties).
- 2,425 were screened (73%): 245 were ineligible and excluded.

#### Survey administration

• Jan-April 2013: **2,180 men were sent a questionnaire** survey based on the PCQ-P (Baker et al., 2008), adapted for Ireland based on cognitive interviews with 17 patients.

### Results

- 1,513 completed surveys were received; 1,499 were eligible for inclusion in the analysis<sup>1</sup>. Response rate = 70.7%.
- 44% underwent biopsy at a National Cancer Control Programme (NCCP) centre (Table 1).
- 53-61% reported having access to a clinical nurse specialist (CNS) at biopsy, after diagnosis, or during treatment (tx); these percentages were higher for men seen at a NCCP centre (Figure 1).
- 52% reported that their overall care was much better than expected; this was significantly higher among those seen at a NCCP centre (57%) or who had access to a CNS (59%) (Figure 2).
- Men with access to a CNS rated their overall care more highly than men who did not (Figure 3).
- Public patients generally reported longer waiting times for hospital referral, getting a confirmed diagnosis and starting tx
  - the % of men who reported waiting <2 weeks for referral, <2 weeks to get their diagnosis, or <2 weeks for tx to start was higher among those with, than those without, private health insurance.
- 57% of men were offered emotional support while awaiting biopsy/test results; 66% received information about their diagnosis; 82% received clear explanations about possible side effects/consequences of treatment; and 75% received information about what could be done about side-effects. These percentages were significantly higher among men with access to a CNS (Figure 4).

## Conclusions

While most men rated their overall care highly, aspects of experience varied between public and private patients. Access to a CNS was associated with better care experiences. Results such as these may inform health service developments.

#### Footnotes

- <sup>1</sup> 14 excluded: 6 did not meet ethical approval requirements; 8 unaware of diagnosis.
- <sup>2</sup> Grouped together, as men unable to discriminate during pre-testing. <sup>3</sup> Chi-square test.
- <sup>4</sup> Men were asked to rate their overall care experience from 0 (I had a very poor experience) to 10 (I had a very good experience).

**Table 1** Characteristics of respondents

Parameter	Response
Age at survey completion	<60 years (20.6%); 60-69 (47.4%); 70+ (32.0%)
Time since diagnosis	<1 year (17.1%); 1-1.5 years (39.6%); >1.5 years (43.4%)
Private health insurance	Yes (60.6%); No (39.4%)
Biopsy at a NCCP centre	Yes (44.4%); No (44.9%); Not specified (10.7%)
Treatment	Any surgery (35.9%); Any radiotherapy (no surgery) (47.8%); Hormone therapy only (1.9%); Active surveillance / Watchful waiting <sup>2</sup> only (8.6%); No treatment identified (5.7%)

Figure 1 Percentage with access to a CNS by care phase: all men and those

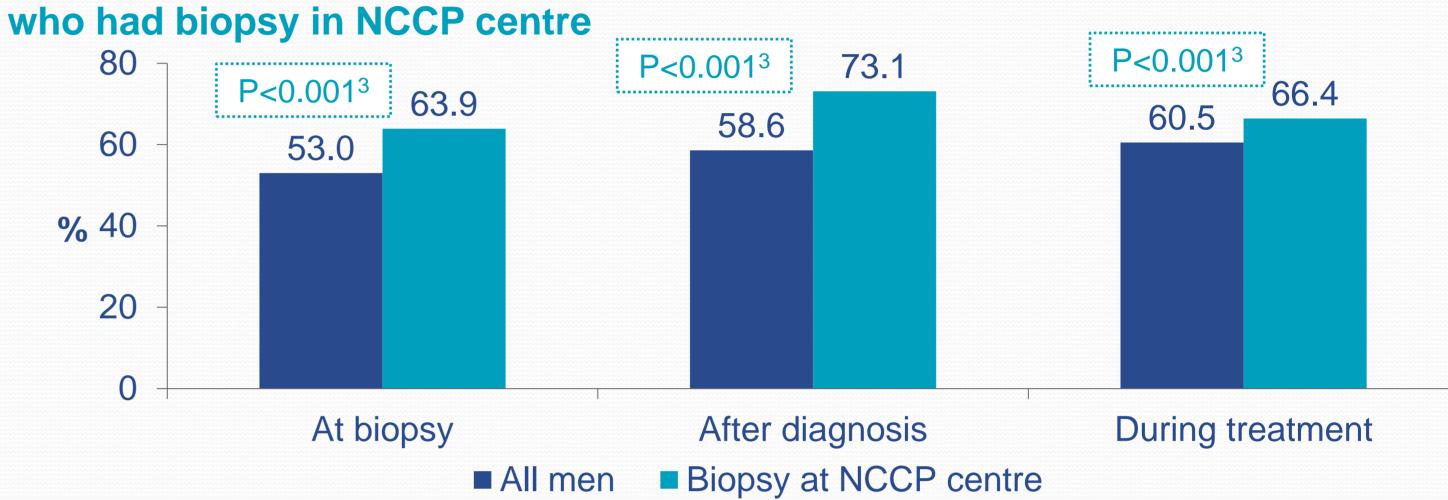


Figure 2 Percentage who rated overall care experience much better than expected: all men and those who had biopsy in NCCP centre and had access to CNS during treatment

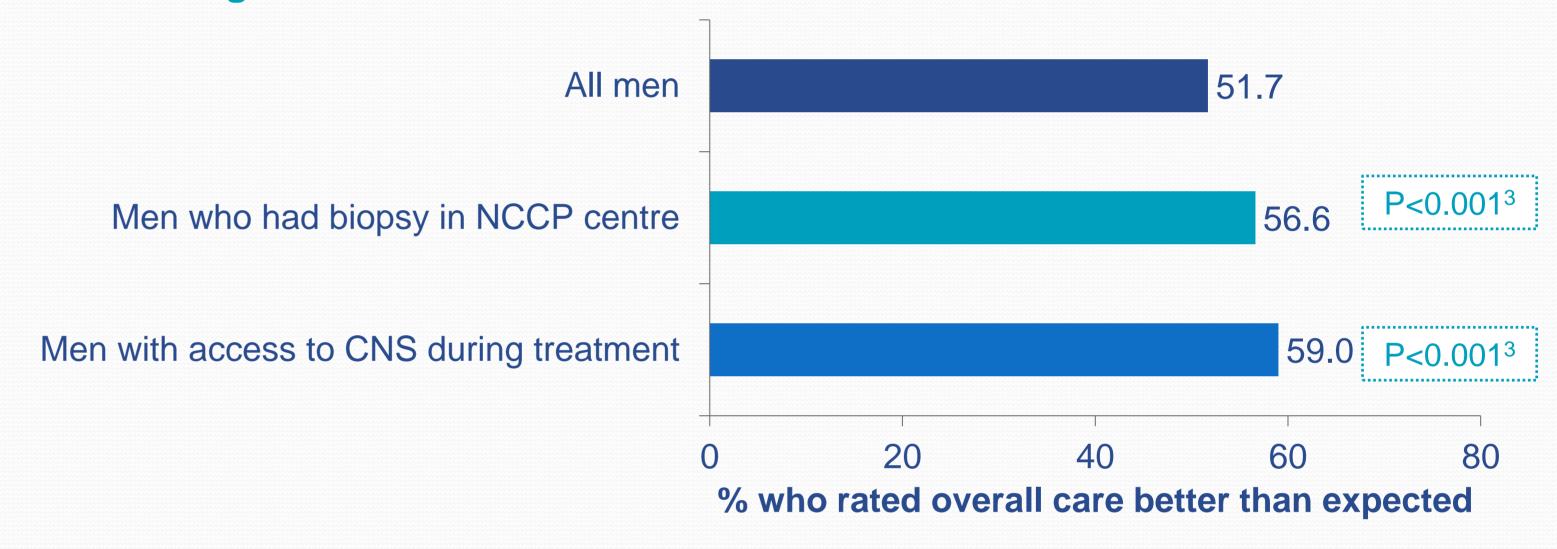


Figure 3 Percentage who assigned care rating of 10/10<sup>4</sup>: all men and according to whether they had access to a CNS at biopsy

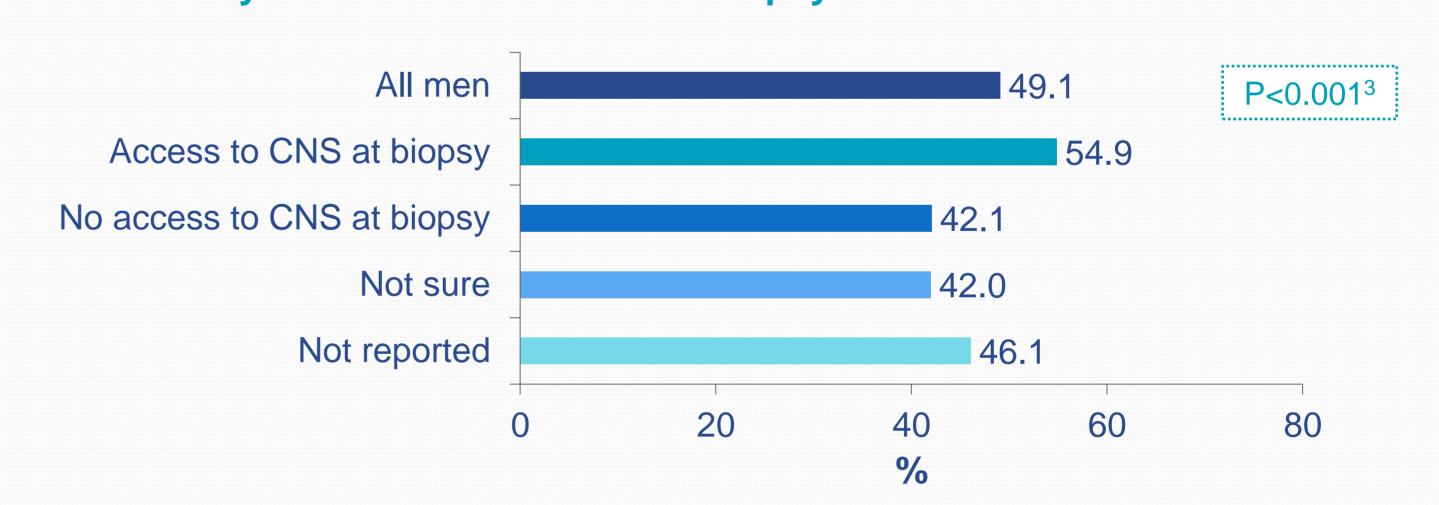


Figure 4 Percentage who reported receiving support and information: all men and men who had access to a CNS at biopsy and after diagnosis

